

The Rapid Syndrome Validation Project (RSVP) TM
Users' Manual and Description
Sandia National Laboratories,
Albuquerque, New Mexico

Contacts:

Principal Investigator^a: Alan P. Zelicoff, MD [apzelic@sandia.gov; 505-844-8020]
System Architect: Susan Caskey [sacaske@sandia.gov; 505-284-5950]
Project Manager: Greg Mann [gremann@sandia.gov; 505-844-8927]

Table of Contents

- 1.0 Introduction
- 2.0 RSVP Tutorial for Practicing Health Care Providers (MDs, PAs)
 - 2.1 Accessing the System : The "Login" Screen
 - 2.2 The Demographics Input Screen
 - 2.3 The Symptoms Input Screen
 - 2.4 The Feedback Screens: What you get is what you give
 - 2.5 The Clickable "Infectious Disease Map of the World"
 - 2.6 Finishing up your Session with RSVP
- 3.0 RSVP for the Epidemiologist: The Query Page
- 4.0 Security: Authentication and Encryption
- 5.0 Frequently Asked Questions
- 6.0 Technical Addendum (in drafting)

Please note: This is a draft document. Several sections have not yet been included pending the implementation of several features of RSVP. Please check back for updated versions of this manual.

^a Please direct any comments to the Principal Investigator by e-mail or FAX: 505-844-8119.

1.0 Introduction

The Rapid Syndrome Validation Project (RSVP)[™] is an Internet based population health surveillance tool designed to facilitate rapid communications between epidemiologists (public health officials in local public health jurisdictions) and health care providers (especially physicians, physician assistants and nurse practitioners). RSVP is designed to overcome existing barriers to reporting of suspicious or unusual symptoms in patients, and capture clinician judgment regarding severity of illness and likely category of disease. For clinicians, RSVP provides immediate feedback with data of relevance to the individual patient reported as well as continuous updating of the geographic and temporal characteristics of symptom distribution in the local community. This includes timely analysis from local epidemiologists (city, county or State depending on locale) as well as alerts regarding serious disease outbreaks based on historical experience or ongoing investigations. For the epidemiologist in the local public health office, RSVP provides real time data reporting, the ability to perform a wide array of the Geographic Information System (GIS) analyses, and a fast, convenient way to communicate with all reporting clinicians on the network.

There were two major guiding principles in creating and implementing RSVP. First, protection of patient confidentiality was paramount over all other considerations. Second, we recognized that clinicians are busier than ever and have little time or interest in complying with additional burdensome requirements in their hectic day; further, we learned that it is the rare physician who has time to keep track of “reportable disease” events in their area and to actually follow-through with the requirements for submitting reports to local authorities. Public Health officials have traditionally depended on specific disease-based diagnostic tests (or the unusual pathognomic symptom complexes such as the rash for measles) for reporting. Inherent in such an approach is delay, and often missed diagnoses should clinicians have no experience with a the identifying characteristics of reportable diseases or should they fail to obtain appropriate laboratory tests. It is well known that cost-control measures are ubiquitous in daily clinical medicine, creating certain disincentives for utilizing laboratory resources. The net result may be fewer channels for tracking and cataloging common (as well as new) infectious diseases across the country and perhaps internationally as well.

Thus, RSVP creates a new environment for reporting of “reportable” infectious diseases and well as suspicious or novel symptoms that may or may not be part of a known disease or disease-complex. As its name suggests, RSVP reporting is based on symptom and sign complexes known as *syndromes*. Syndromes can be defined with a high degree of specificity in mind – e.g. hemorrhagic fever syndromes – or can be made more general, reflecting common parlance in medical care and communication among doctors. Although there are no strict rules for development and promulgation of syndrome definitions, we chose to

DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

organize syndromes around organ systems, taking into account the use of descriptors that characterize severely ill patients whose appropriate disposition (admission to the hospital, observation in a holding unit in an outpatient setting, or perhaps close observation at home with scheduled follow-up) is the first clinical priority. It is very common for physicians to describe patients with phrases such as “a 30 year old female with fever and suspected central nervous system [CNS] infection”, or “an elderly male with fever and influenza-like illness”. Because such descriptors have almost universal acceptance, we chose from the beginning to adopt this syndrome-complex approach in identifying patients that are likely to warrant sufficient attention that reporting to public health officials would be of importance for surveillance per se, along with the clinical care of the patient.

There are six syndrome complexes in RSVP:

- Influenza-like illness
- Fever with skin rash
- Fever with suspect CNS infection (formerly “fever with mental status changes”
- Severe diarrhea (watery or bloody – it’s up to the physician to decide what “severe” means)
- Adult Respiratory Distress Syndrome [ARDS]; and
- Acute Hepatitis

These syndrome complexes were developed as a result of exhaustive discussions among public health officials and practicing clinicians. We believe that they capture the vast majority of diseases of public health importance, including, but not limited to diseases that could occur as a result of bioterrorism: the intentional introduction of infectious organisms or toxins to create morbidity and panic in a population.

We noted early on that clinicians, in general, are quite good at identifying patients who are well-described by these syndromes. At the same time, and equally important, they are easily able to identify patients who do not. For example, “influenza-like illness” (by far the most common of the syndromes listed above) refers to patients who have high fever, severe myalgia, headache and/or sore throat, weakness, prostration and/or listlessness, arthralgia, lymphadenopathy, and cough. Patients with rhinitis and mild fever, isolated sore-throat, cough with sneezing do not fit into this category. Thus, the utility of RSVP depends on clinician judgment for reporting; the kind of judgments that physicians and mid-level providers make dozens of times a week. Public health officials are most interested in knowing about patterns of severe illness in their area of jurisdiction; timely prophylaxis and notification to the population may make have an enormous impact on hospital admissions, death, lost-work and school time as well as overall suffering. It is these patterns that RSVP is designed to rapidly identify; in so doing, we believe that clinicians and their patients

DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

benefit, especially if analysis from public health officials assists in early diagnosis and efficient employment of medical resources.

Clinicians and their patients are the “smart sensors” in any disease outbreak. Without timely reporting, awareness of public health authorities is likely to be outstripped by disease progression, particularly in the setting of communicable infectious disease. Recognizing the critical role that clinicians play in identifying and mitigating the consequences of infectious disease, we have carefully constructed the RSVP reporting interface to meet the following requirements:

Data entry, including demographic as well as clinical information must be:

- Fast (less than 45 seconds of clinician time for each case entry, and preferably even less than that)
- Inexpensive, requiring no downloads of special software at any time
- Simple and without ambiguity
- Intuitive, so that no training is required; and
- Error-free, obviating correction and re-entry

Feed-back to clinicians must:

- Be immediate (less than 10 – 15 seconds)
- Relevant to the patient that the physician is seeing
- Of importance for the differential diagnosis; and
- Provide information on similar cases seen recently by other clinicians in the community.

For RSVP to be of relevance to Public health officials, a separate (though sometimes overlapping) set of requirements must be fulfilled:

The system should automatically notify officials of reported cases that closely match disease entities of *local* prevalence or importance (e.g. Hantavirus in New Mexico, food-borne botulism in Alaska, or Dengue in southern Texas)

GIS tools should be included to facilitate easy analysis

Advisory messages to clinicians must be easy to update, perhaps even several times a day

Data base structure should be compatible with existing medical database standards; and

Specific queries should be easy using automated interfaces and standard “natural language-like” lexicon.

For such a system to be sustainable on its own merits (particularly in the current cost-containment environment) it must improve the effectiveness of clinicians and public health officials in their day-to-day work.

2.0 RSVP Tutorial: Screen interfaces and Demonstration

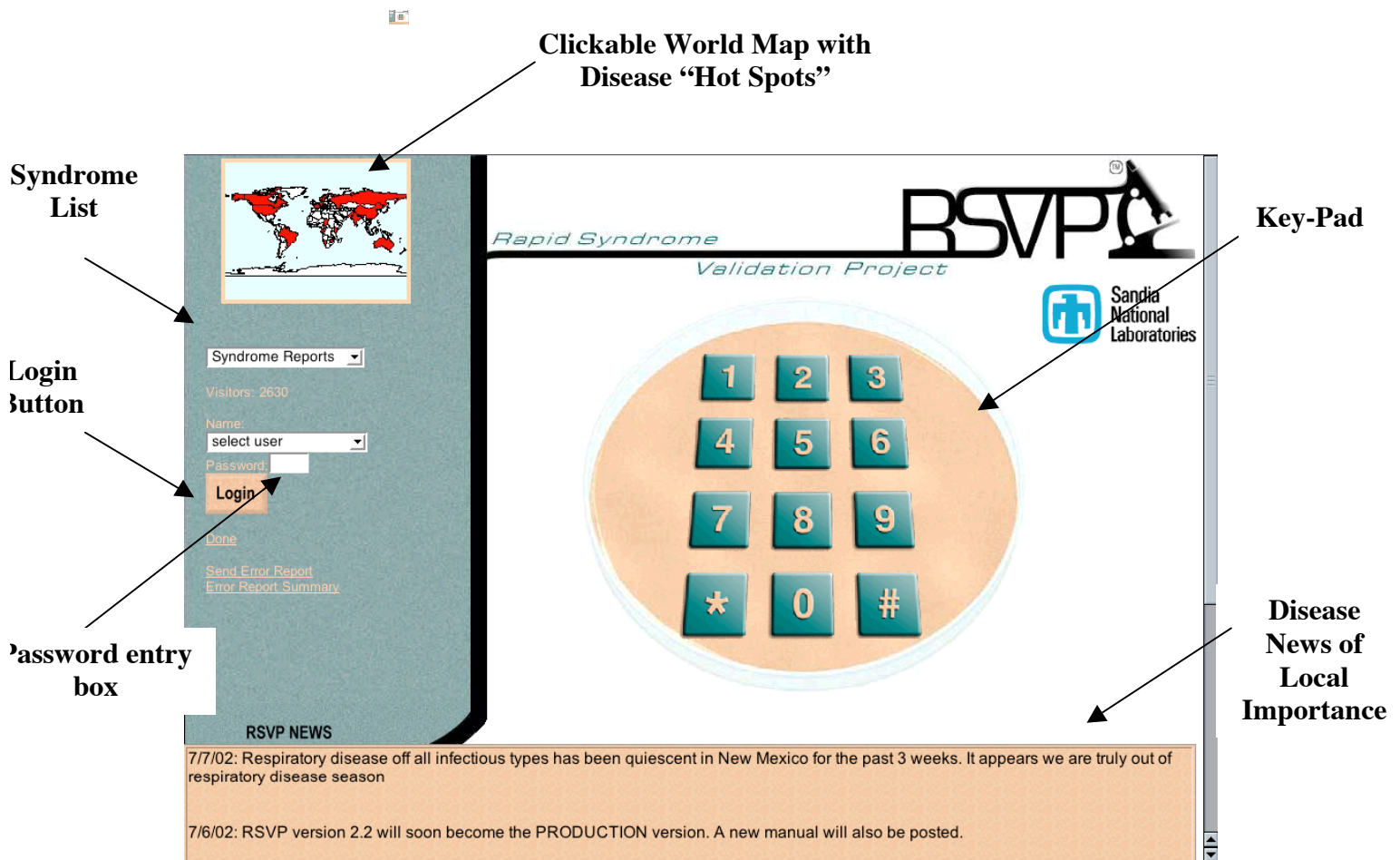
There are five screens in RSVP, 1 for Logging into the system, 2 for input of data and 2 for feedback to clinicians.

2.1 – Accessing the system on-line: The “Login Screen”

Users can quickly learn the features of RSVP and the simple process of data entry by pointing their web browser (Internet Explorer 5.0 or later; Netscape 4.7 or later on either PCs or Macintosh) at the DEMO site, which is:

<http://rsvp.sandia.gov> [note: no “www” is required]

This takes you to the main homepage of RSVP (demonstration site – there is another address for the “real site”). Choose “NM Demo site” to proceed with the tutorial. On the next page, choose “SNL Data Entry” from the “Select Clinic” pulldown menu. At long last, you arrive at the LOGIN screen:



DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

Users will note the following (starting on the left side of the screen and going counter-clockwise):

1. On the left hand side of the screen is a listing of each of the **six syndromes**. They are in a pulldown menu, so you can select on any one of the syndromes to immediately go to the “**Feedback Screen**” (see more detail below) that lists interesting and (we hope) useful information to the clinician and epidemiologist.
2. The “**Select Users**” pull-down list shows all of the people who are permitted to use RSVP from the facility where you are located (in the demonstration setting, you can choose any of these names). Each user has a unique password.
3. The **Password Entry Box** is where you enter your password using either the **Key Pad** (which you can click on with your mouse, or, if you are using a touch sensitive screen, you can use with your fingers by touching each number). You can also type in your numerical password using the keyboard on the computer if you prefer.
4. The **Login Button** is what you click on (or touch if you have a touch-sensitive screen) after you have selected your user-name and entered your password. This will take you to the next page (called “Demographics” – see below)
5. In the lower left hand corner there are several links that allow you to report any problems or errors that you find to the system administrator at Sandia, look at recent error reports and whether or not the problem has been resolved, and, link to a form (which differs for each public health jurisdiction) that gives you on-line access to standard disease-based reporting. There is also a news box that announces any upgrades, improvements, or new features to the system organized by date, with the most recent news first. You can scroll down this news box using the scrolling bar on the right hand side of the box.
6. At the bottom of the screen is the **Local Disease News** of clinical importance. Here you will find the latest up-to-the-minute announcements directing you to the news box or warning you system problems. This information is updated by the local public health authorities in your area.
7. The **KeyPad** is where you enter your password (assuming it is numeric, as it is by default – meaning “unless you ask for something otherwise”). If you have a touch sensitive screen, you can “press” these buttons on the screen, otherwise you can just point to them with the mouse and “click” to “press” them.
8. And circling around to the top left hand corner is the **Clickable World Map of Disease Hot Spots**. As you’ll see below, this is a *constantly updating* map and if you click on the map (don’t do it yet) you’ll get a much enlarged map of the world. Each country in **RED** has had some

important human *or* animal infectious disease outbreak within the past thirty (30) days. So, you can get a quick idea of what is happening around the world, and if you happen to see a patient from, say, Mexico or Australia (or whatever country happens to be colored **RED** at the time, you can get much more information about infectious diseases (as described in section 2.5 below).

2.2 The Demographics Screen

“Demographics” is the “where, when and what” of epidemiology. It describes the patient in some detail (but no names or addresses or other patient identifiers are used to protect patient confidentiality), including sex, occupation, recent travel (if any), and rough estimate of patient age. When precision of data is not necessary for epidemiologists to do their analysis, we have removed that precision, again to protect against any reasonable possibility of linking a specific report with a specific individual. For example, in trying to understand (from the epidemiologists’ standpoint) the vast majority of outbreaks, it matters little if a given patient’s age is 20 or 21 years. However, if the patient is 65 to 75 years old and not, say, 30 years old, such information speaks volumes about the likely disease entity involved, and perhaps even the origin of the disease.

Throughout the process of designing the Demographics screen and all of the rest of RSVP, patient confidentiality was our prime concern. You will see that reflected throughout the user interfaces, as well as the details of the way the server handles all data.

The only piece of information that *must* be entered before continuing to other screens is a Zip-Code of home or work. Zip-Codes are accessed through the pull-down menus (see Figure below), and are specific for each facility, capturing all Zip-Codes within about 100 miles of the facility.

DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

Zip Code pull-down menus (for home or work or both)

Patient Descriptors

Syndrome Selections

RSVP Control Buttons

High-Risk Occupation Check-List

DEMOGRAPHICS

Facility: SNL

Clinician: Al Zelicof

Zip Code (Home)
(Alt Home Zip)

no selection

Zip Code (Work)

no selection

Travel?

Y

N

Occupation

☐

Child Care/School/College Student

☐

Healthcare Professional

☐

Food Handler

☐

Agriculture☐☐☐☐

Contact with person with similar illness?

Y

N

Gender

M

F

Age

< 5

5 - 18

18 - 30

30 - 45

45 - 60

60 - 75

>75

Hospitalization Status

Admitted

Not Admitted

May Be Admitted

Syndrome:

Undiff Febrile or Influenza Like

Fever with Skin Findings (rash)

Fever Suspect CNS

Acute Bloody Diarrhea

Acute Hepatitis

ARDS

Logout

Cancel

Contact Local DOH

DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

Other items on this screen are:

Buttons for Travel (if you choose “Yes”, the system will prompt you with two additional buttons “US” and “International”, and if you choose “International” the system will prompt you for the area of the world your patient had traveled). You will see this motif repeated on the “Syndrome” screen – see below.); Gender (Male or Female), Age (which is in ranges to protect patient confidentiality) “Syndrome” selection buttons to select the proper category in which to place the patient you are reporting

Control buttons, which enable you to either Logout, Cancel this particular entry, or to send an Alert to local public health officials about this case.

A list of potential “high-risk” occupations that you can check (either single or multiple selections are permitted, and if you feel that you are seeing someone who is an un-listed occupation that puts them at risk for infectious disease you may click on “Other”).

And you can indicate whether or not the patient has been admitted (or might be admitted), obviously another important indicator for severity of illness.

Note that when you “click” on a button or a check box, the item will turn **RED**. You can turn it “off” by clicking on it again, or selecting its opposite (e.g. “M” for Male can be changed to “Female” just by clicking on the “Female button”; it’s pretty intuitive so don’t be afraid to try it out). It should take you only a few seconds to enter the Zip Code and patient information. When you are finished, select a syndrome and another screen will appear.

2.3 The “Symptoms” screen (really Symptoms, Signs and Labs)

Each of the “symptoms” screens in RSVP is unique for the particular syndrome you have chosen; we invite you to look at each of them using the Demo site. For illustration purposes, the “Influenza-Like Illness” (ILI) symptom screen is shown below, as it is by far the most common syndrome and it has the most detailed reporting information, though you will see that it is not very complicated at all.

DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

**Symptoms Data
Entry Buttons**

**Signs Data Entry
Buttons**

**Laboratory Data
Entry Buttons**

Undifferentiated Febrile Illness OR
Influenza-like Illness

History/Symptoms

Cough

URI Symptoms

Conjunctivitis

GI Symptoms

Headache

Myalgia

Signs

Temperature

Increase Respiratory Rate

O₂ Sat.

Abnormal Lung Sounds

Stiff Neck

Rash

Labs

Platelet

WBC

Chest X-Ray

**Control
Buttons**

DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

Physicians and other health-care providers will find this screen to be very intuitive and easy to use. All of the symptom screens are organized in the same way: symptoms at the top, signs (i.e. physical examination findings) in the middle, and labs (should any be obtained) at the bottom. **Note that NONE of this information HAS to be entered**, but it is obviously better for the public health officials who are analyzing submitted reports if they have additional clinical information from this screen.

When you click (or, touch) on many of the buttons on the symptoms screen, addition buttons will pop up asking you for more information. For example, if you indicate that the patient has a cough, the system will ask you to describe it by giving you a choice of three buttons: Productive, Non-Productive and Hemoptysis. You will find that you can NOT select BOTH “productive” and “non-productive” (that would make no sense), but you CAN select “Productive” and “Hemoptysis”. Consistent with our philosophy to not burden clinicians, you do not have to respond to any of these prompts.

We have chosen the listing of “Labs” very carefully. Astute clinicians will immediately note that these are the kinds of lab tests that would be ordered if needed to make a disposition decision; further, these labs (and X-rays) would be available in a short time to the provider. So, in most cases, it would be possible to include these results in the report. But, as always, the clinician need NOT enter any of this data.

Finally, there are some reminders for clinicians built in to some of the buttons; they are there to ensure that certain specific (though generally rare) results are not missed. For example, if you click on “Abnormal” in the Chest X-ray field, the system will prompt you further with four additional descriptors: Focal Infiltrate; Diffuse Infiltrate; Effusion; and Wide Mediastinum. The latter descriptor is often missed when chest films are read. More to the point, this particular finding in the setting of a febrile, influenza-like illness is virtually diagnostic of anthrax, especially if there is high fever and hemoptysis. It is true that other illnesses can cause a wide mediastinum (Hodgkin’s disease, Sarcoidosis, and acute Coccidiomycosis to name but a few). However, with an acute ILI, anthrax rises rapidly to the top of the differential diagnostic list.

One final point: if you select “Y” for Rash, this is the one and ONLY time that RSVP brings up another screen that permits you to “describe” the rash by selecting amongst well-accepted dermatologic terms (that are often forgotten by non-dermatologists). Just point and click, or, if you don’t want to describe the rash, just hit the close button on the Rash

DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

window. Eventually, as Internet and micro-electronics technology improves, RSVP will enable you to take a digital picture of the rash and upload it to the RSVP system to be seen by everyone. But, that's a little bit in the future.

Well, now you are done with the data entry. You will see buttons that provide for comments (a separate screen comes up in which you can type), and also to notify public health officials immediately about your case. But usually, physicians will just hit "done". At that point, the "Feedback Screen" will activate. In addition, a few other things happen (see below).

2.4 The Feedback Screen

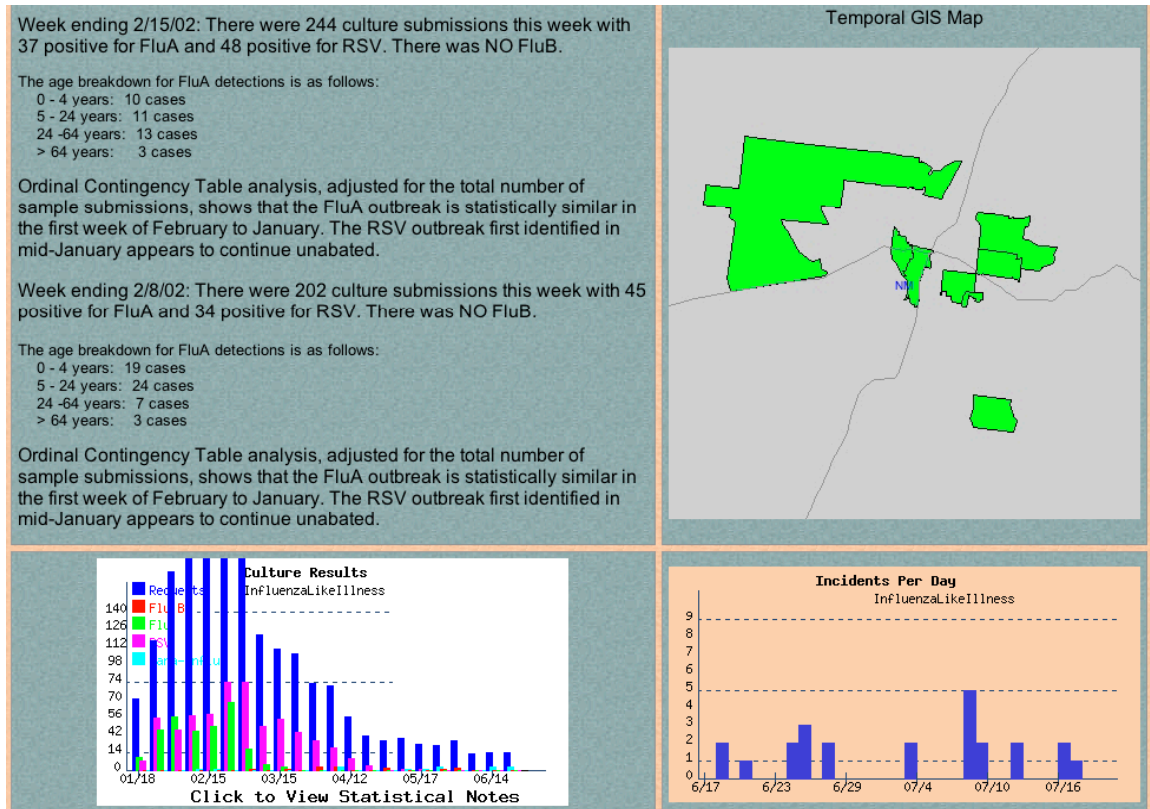
As soon as you are done entering the case report, three things happen:

- First, the data is both *encrypted* and *authenticated*. Most people are familiar with encryption, but if not, it means that the data is scrambled in such a way as to make it very difficult for someone who might be watching the data flow out of your machine understand what it means. Most web pages use some degree of encryption, and RSVP uses a high level of encryption. It is nearly impossible to "crack" the encryption code (although, in principle, someone *could* do it if they have access to a super-computer and several years of time). *Authentication* is much trickier (and much more important); this word means that the RSVP server checks to see if the data is coming from a registered site (this doesn't happen on the demo version of RSVP). In other words, even if someone knows your username and password, if their computer isn't appropriately registered ahead of time with the system, RSVP will not record the data. This prevents "bad" or "unauthorized" data from entering into the RSVP database.
- Second, the information is screened for certain combinations of signs, symptoms and lab results, determined by local epidemiologists to be strongly correlated with diseases of public health importance in their jurisdiction. [As but one example – in New Mexico, fever and ILI in a young person with diffuse infiltrates on chest X-ray is Hantavirus pulmonary syndrome or plague until proven otherwise]. The signs/symptom/lab combinations vary from syndrome-to-syndrome and from place to place in the country. Should the clinician happen to select data that meets the criteria of the local epidemiologist, RSVP will notify the epidemiologist on call (by e-mail, FAX and/or digital paging) of the case within about 1 minute. Included in the notification is the name of the reporting physician and the facility telephone number.

DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

The epidemiologist can then make a decision to call the reporting physician or not.

- Third, a feedback screen, summarizing all reported cases of the same syndrome, is presented. The feedback screen looks like this:



The Feedback screen is a dynamic document, changing after each report is submitted. It is a combination of automated mapping and graphing functions, an advisory message from local public health authorities (which they can update as frequently as they feel necessary), and culture data for organisms of relevance to the syndrome in question.

In this sample feedback screen, the local advisory message is seen in the upper left hand corner, and it represents the net assessment of experts in the public health office of disease patterns and other data of immediately utility to the physician caring for the patient just reported (and potentially for other patients as well); the local public health officials – who are the key “analysts” in the RSVP system, update this information as they deem appropriate. In the lower left hand corner is a graph (going back several months or more depending on the locale) of all culture results of major

DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

pathogens causative of the syndrome. It is easy for clinicians to see patterns or to use the results for “index of suspicion” decisions.

In the lower right hand corner there is a temporal (“time”) graph of all cases of ILI reported in the past 30 days. This is the famous “epidemiology curve”, and it may be useful to both clinicians and epidemiologists to determine if they are seeing a true epidemic (based on historical records or experience), or if reports are sporadic. Coupled with the temporal graph is a geographic map that is displayed in the upper right hand corner of the Feedback Screen. It is centered on the facility that is doing the reporting (in this example, you are actually seeing the crossroads of I-25 and I-40 where Albuquerque is located; you might not recognize it if you don’t live in the area, but all of the local physicians do). The colored areas are zipcodes where there have been reports of similar patients in the past 30 days, color coded by number of cases.

There is another map in the epidemiologists’ page where you can zoom, do queries of all types (like socio-economic status of the zip code(s) in which patients are fine – but not for individual patients, of course), look at geographic features that might be relevant for doing disease analysis, etc. We don’t routinely make this available for physicians (mostly because physicians and other health care providers don’t have time to do correlations and statistical analysis) but physicians are welcome to look at the same data that the epidemiologists do (see below).

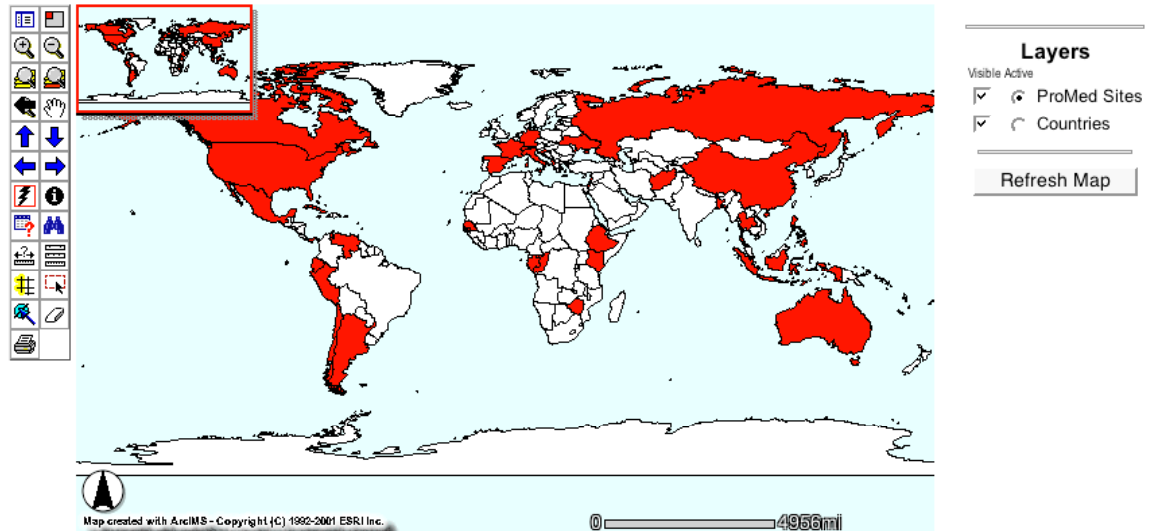
2.5 The Clickable Map of the World

On rare occasions, physicians will see patients in their offices who have recently traveled to (or come from) countries outside the US. Most physicians don’t have an easy way to know “what is going on” from the infectious disease standpoint in places outside of their local area (and, frankly, sometimes physicians don’t even know what is going on across town or even in the office next to them); but, if a doctor is thinking about a patient in the exam room with fever and rash from, say, a country in central Africa, she’d sure LIKE to know what is going on there.

The Clickable Map makes it easy. Here’s how it works: first, click on the little map in the upper left hand corner of the Login page. You’ll get a new window that looks like this:

DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

ProMed ProMed ProMed ProMed ProMed ProMed ProMed ProMed ProMed ProMed



There are several things to point out about this map. First, as noted earlier, any country that is colored RED has had a significant disease outbreak within the past 30 days in either humans *or* animals. The reason we did this is that there are many zoonotic diseases (e.g. anthrax) that often affect animals before, or at the same time that humans are affected.

On the left hand side of the map are “tools” that you use to query the map. We’re only going to discuss a few of these here (the ones of most use to a busy practicing physician), but we invite you to try them out. Most are pretty intuitive. For example, the seventh icon in the first column of “tools” on the left hand side looks like a lightning bolt. Click on it (it should get a thin red box around it). Then click on any of the countries colored in RED on the big map. When you do, a separate window will come up with specific information on that country and its disease outbreaks of importance.

Three publications populate the RSVP Clickable map data base. They are:

PROMed (an on-line product of the Federation of American Scientists and some 2,500 epidemiologists around the world). PROMed is an edited epidemiology news service (you can get it by e-mail for free, but most docs don’t have time to plow through it to get the information they way), so it is reasonably authoritative. And, it is very prompt, as the editors (volunteer epidemiologists from around the world) get lots of input from their close colleagues, most of whom they know personally.

Morbidity and Mortality Weekly Report (MMWR) of the CDC. This publication is VERY authoritative, but often rather slow in

DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

getting important news out. Most physicians receive MMWR (and a few physicians read it on line), but it comes by the mail so it is even slower than slow. Making it available in a “clickable” map helps to make it more relevant to daily clinical practice.

The World Organization Bulletin. Once again, this is a VERY authoritative source, but it is limited in its scope, and since most things at WHO are done by consensus, the delays can be quite long before important data is shared with the practicing physician.

Play around with some of the other tools. For example, the “i” with a circle around it (right next to the lightning bolt) gives you country specific information if you click on the “i” and then click on a country. The magnifying glass lets you “zoom in” on the map.

Remember that when you use the “Clickable Map” tool, a great deal of information has to be uploaded onto your computer, so be patient. Sometimes the Internet gets bogged down with huge data transfers, and that can make the waiting a bit longer than you want it to be. But, it’s worth it.

2.6 Finishing up

After you are done studying the map, you can close it by clicking on the close box in the browser window. The Feedback screen is exited by selecting the “Done” button in the upper right hand portion of the screen.

3.0 The Query Page: Tools for the Epidemiologist

For the technical types in the audience, RSVP stores its data in two formats: a COAS compliant database and an SQL (“Standard Query Language”) compliant database. The former exists so that RSVP data is accessible by other large medical software programs that conform to the HL-7 standard; the latter exists to make accessing the data easy for the non-database expert. The rest of this section is devoted to the non-database expert.; additional technical details on the structuring of the database can be found in section 6.0 of this manual.

The feedback screen (see **Section 2.4** of this manual for an introduction) is the first tool for the epidemiologist. With it, she can see the epidemiology time curve and the geographic distribution of reported syndromes within their jurisdiction and in other reporting areas of the United States (and, as RSVP grows, in other countries as well). The epidemiologist can zoom in and out to anywhere in the world (we default with a zoomable map of the US for US-based epidemiologists), and do a wide array of “hypothesis testing” queries.

DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

There are 3 additional tools that augment the analytic efforts of the epidemiologist: raw data retrieval (for importation into the epidemiologists favorite statistics package; a “GIS map overlay” tool; and a time-lapse movie. We will take these each in turn. To try them out yourself on the demo site, do the following:

Go to the main RSVP web page: <http://rsvp.sandia.gov>

Select “NM Demo Site”

Then, from the new page that comes up, select “Regional Data Query”

Log in as sacaske@sandia.gov from the pulldown menu and type in the demo login password, which is “1234” (without the quotes).

3.1 Raw Data retrieval

As noted earlier, RSVP data is kept in two formats, one of which is called the “Standard Query Language” [SQL] format. SQL permits easy extraction of data from the large database that has information on each patient record, organized by syndrome, with all data entry elements in place. Obviously, in most cases, the entering physician will not choose to enter data for every data element. For example, in reporting a patient judged by the physician to fall into the “Fever with Skin Rash” category, the physician may not click on the temperature button to indicate the degree of fever. In this case, RSVP has a blank field (or a “Data Not Entered” entry in the data item for temperature for that patient.

This is to be expected; physicians are busy and may not have sufficient time to enter in all of the data. But that does not prevent statistical analysis from being done. As most epidemiologists know, statistical techniques have been developed to take into account missing data items. The important thing is accessing the data in the first place.

RSVP makes data access easy, and imports any data that the epidemiologist requests into an Excel spreadsheet. The vast majority of epidemiologists are familiar with Excel, and more important, most statistics packages permit the user to import data from Excel spreadsheets. At a minimum, users can cut and past data from an Excel spreadsheet into the statistics packages with which they are most familiar.

In order to create the Excel spreadsheet, the epidemiologist goes to the “Query Page”, whose link is found on RSVP’s initial **Login Screen** (see **Section 2.1**). Just click on the link, and you will be asked to select your username from the pull-down menu, and to enter your password. Note that access to the raw data is limited to the jurisdiction in which the epidemiologist resides (or for which she has a password or user account). This is done to protect information at the level of local public health jurisdiction; local epidemiologists are, of course, free to distribute the data from their jurisdictions to anyone they chose, and RSVP simplifies this

DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

process by creating an Excel spreadsheet which can then be easily faxed or e-mailed.

Once at the query page, users will see the following screen:

Submit Query for display as a WebPage

Select one or more Syndromes:

Influenza Like Illness
Fever with Skin Findings (Rash)
Fever Suspect CNS
Acute Hepatitis
Acute Bloody Diarrhea
Acute Resp Distress

Facility:

SNL

Date:

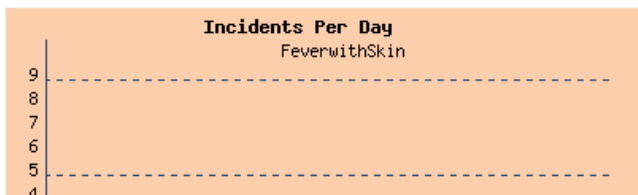
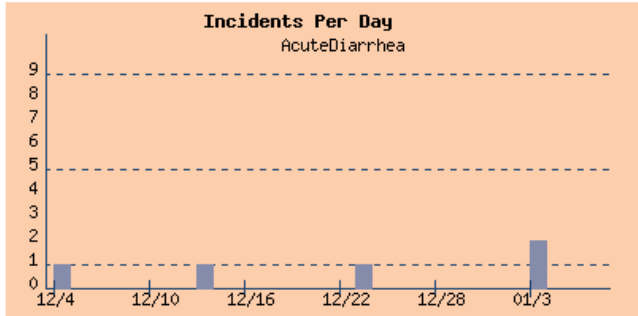
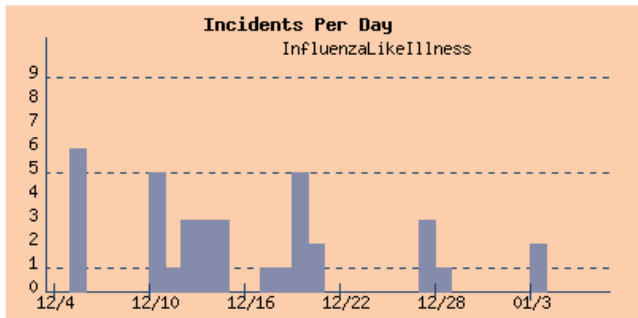
2001-10-31 00:00:00
2001-11-01 00:00:00
2001-11-02 00:00:00
2001-11-04 00:00:00
2001-11-05 00:00:00

Submit

[Display in Excel](#)

[Graphs](#)

[DONE](#)



Note on the left hand side (LHS) of the screen there are three scrollable windows. The first, near the top of the LHS lists each of the syndromes; the second list each of the reporting sites within the public health jurisdiction; and the third lists dates of data entry. In order to generate the Excel spreadsheet, do the following:

- Click on the hyperlink "Display in Excel Spreadsheet"
- Select the syndrome(s) you are interested in by clicking one or several within the first scrollable window (you can use standard Windows and Mac conventions like Control-Click to select several syndromes)
- Select the reporting site(s) you are interested in by selecting them in the second scrollable window.

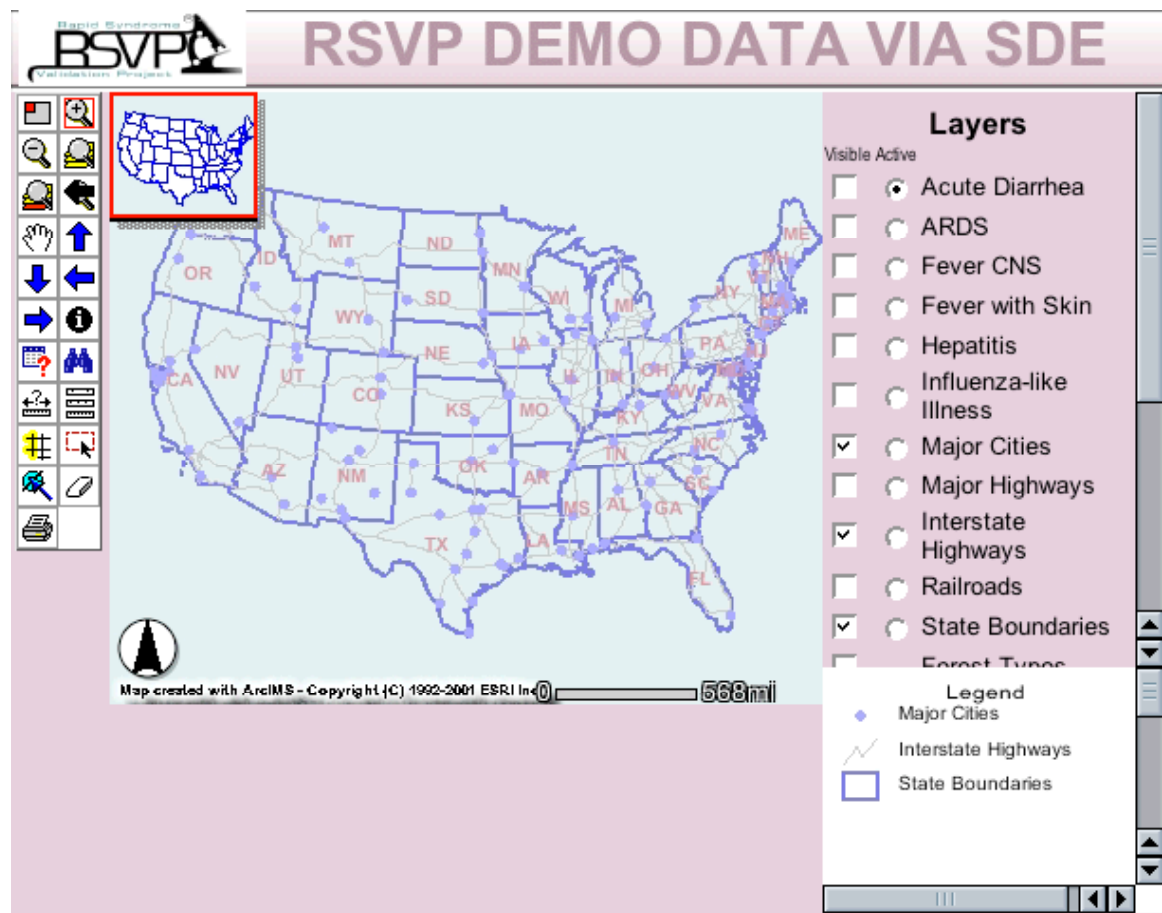
DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

- Select the day, dates, or range of dates you are interest in within the third scrollable window (you can use the usual conventions of “Shift-Click” to select a range of dates).
- Hit the “Submit” button

And PRESTO! You will have an Excel spreadsheet that you can now save on your computer and use for later analysis using the statistics package of your choice (or Excel’s statistical analysis tools). This is very convenient, in addition, for e-mailing to your colleagues in public health who might be willing or able to assist with data analysis.

3.2 Map Overlay Tool

On the lower LHS of the same screen is a link to “GIS Map”. When you click on it, you’ll get a screen that looks like this:

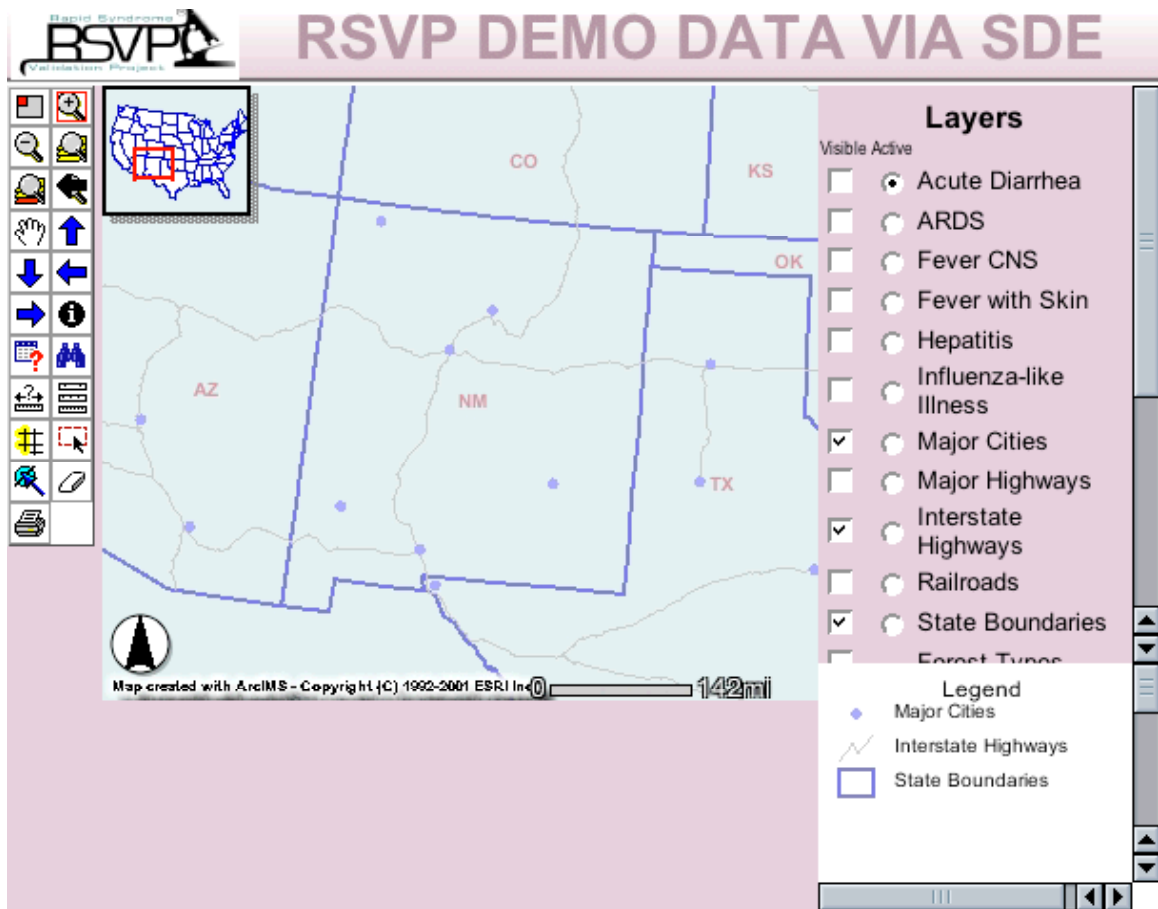


Now, once again, there are tools on the left hand side, and something new on the right-hand side (RHS) called “Layers”. These are the items that you want to display on the map while the tools help you manipulate the

DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

map. Let's try an example, and then you should be able to try out other things on your own.

Click on the first icon in the second column of tools on the LHS (it is a magnifying glass with a "+" sign in the middle meaning "zoom in"). Then click somewhere in the middle of New Mexico on the map (if you don't know where NM is, we can't help you). Click another time or two until the state of NM occupies more or less most of the visible area of the map. You should see something like this:

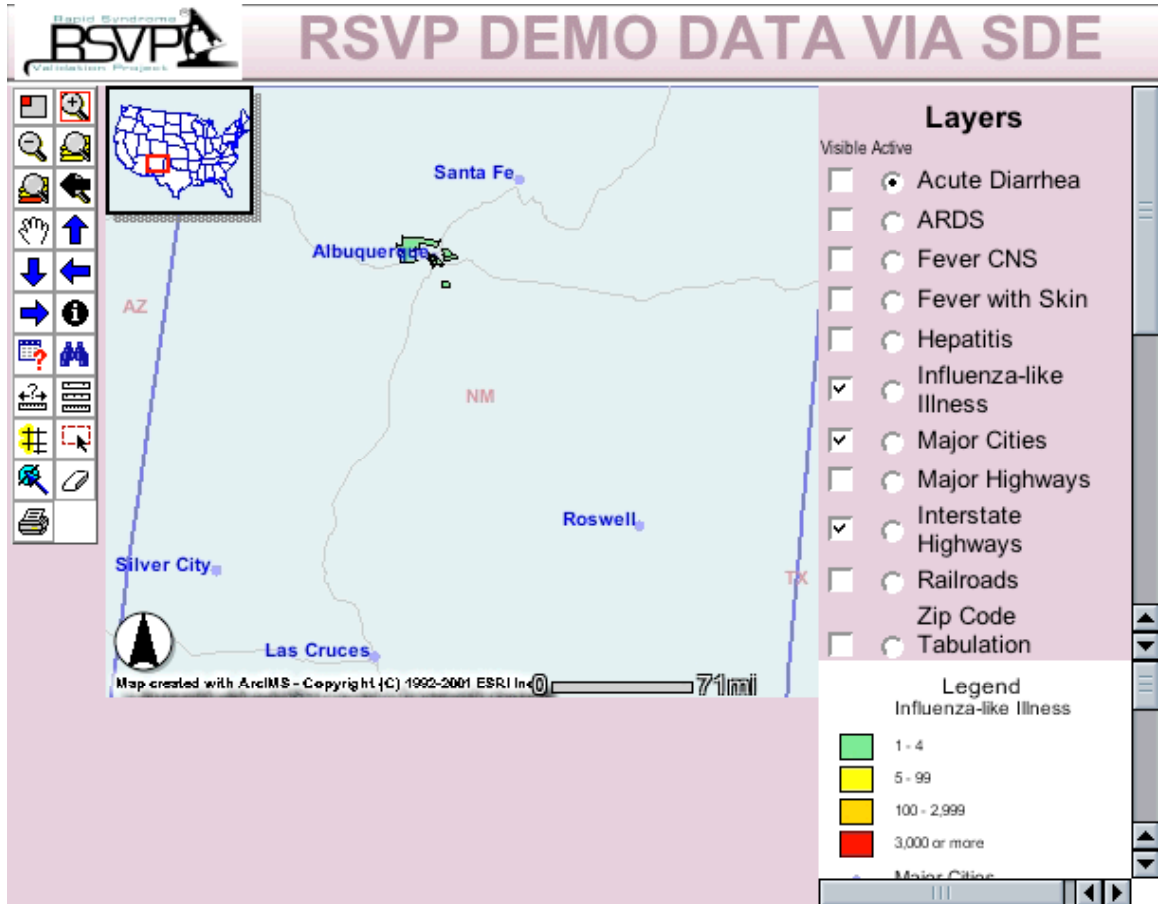


You will also note that the "Legend" for the map in the lower right hand corner changes. Note also that the "Visible" layer boxes next to "Major Cities", "Interstate Highways", and "State Boundaries" were already checked when you started things up, which is why you can see the major cities in the area, the highways, and state boundary lines.

Now let's do a little hypothesis testing. Suppose we want to see all reports of Influenza like illness and see if they are occurring near areas of forest or tree coverage (where, say, *Hantavirus* harboring mice hang out).

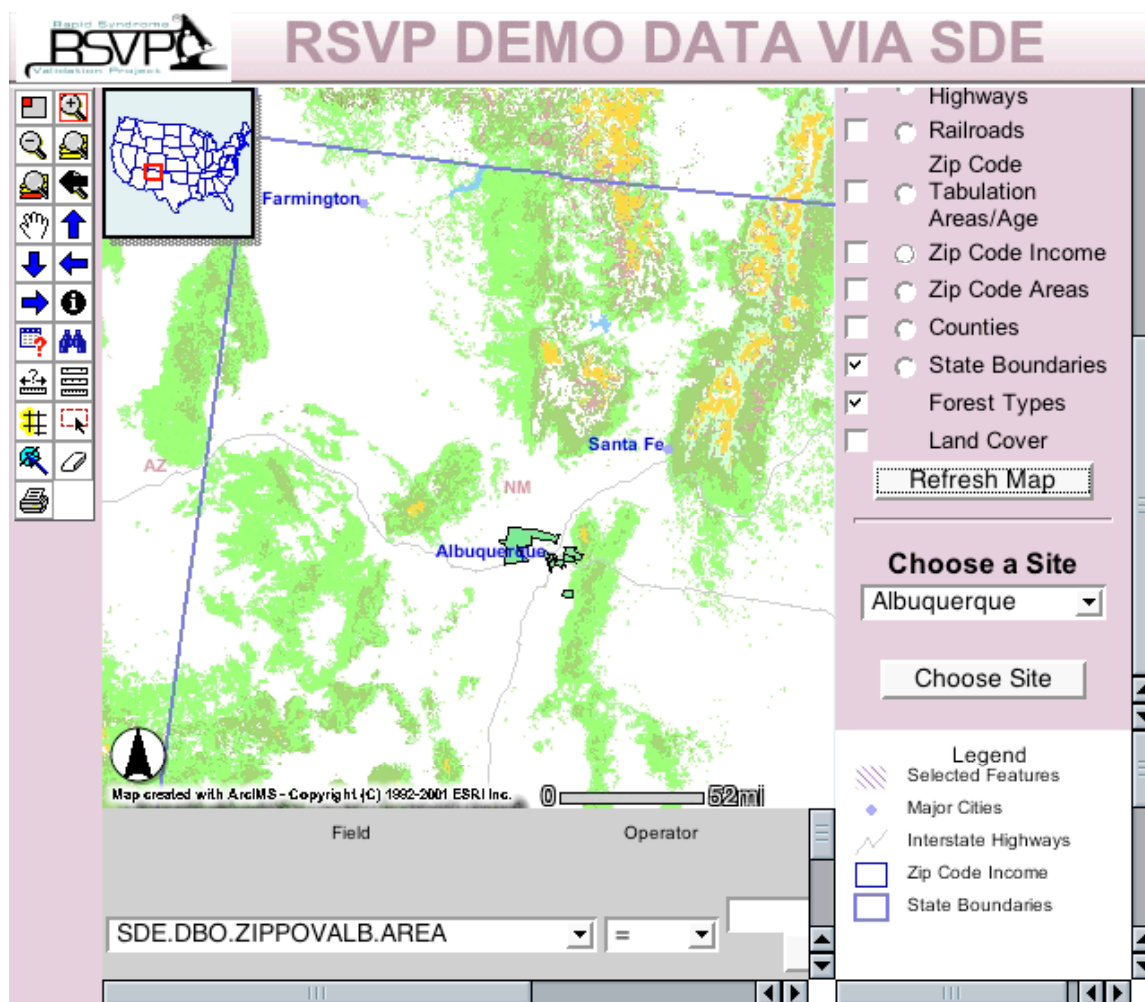
DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

Click the “Visible” box next to Influenza like illness and then hit “Refresh Map” at the bottom of the Layers frame (you may need to scroll down to see it depending on how big your screen is). You will then see a screen that looks something like this:



In the center of the state, around Albuquerque, various Zip Code areas that have reported cases of Influenza like illness light up. Zoom in a bit to see them clearly (we already did in the picture above).

Now let's see if these cases are occurring in the heavily forested areas of the State. Scroll down the layers layer until you see “Forest Types” and click on “Refresh Map”. Now, a bit of data transfer has to take place (so be a bit patient), but you'll be rewarded with something that looks like this:



Now you can see that there is little correlation between cases and “green-ness” (or where there is forest coverage). Hence it is unlikely that the symptoms that are being seen in the human population emanated from something in the forest (like Hantavirus or Bolivian Hemorrhagic Fever); it doesn’t mean its IMPOSSIBLE, just that other things ought to be considered.

There are many, many other tools, including the ability to do socio-economic factor correlation. More detailed descriptions will appear in upcoming versions of this Manual.

3.3 Time-lapse movie Tool (in progress)

Epidemiologists and other disease analysts often want to get a quick picture of what has been happening over time and space with a given syndrome in the population. This tool, when implemented, will permit you to select a syndrome, and the period of time over which you want to see its map displayed, as a movie. The RSVP server will build the movie on demand and send it to you. If you have a slow Internet connection and choose a long period of time to review, it could take a while for the movie image to upload. We are using “streaming” technology to keep the wait time down to a minimum; on a fast Internet connection (say, a DSL line or cable modem) you’ll hardly notice it. With a modem connection, it will most certainly take longer.

3.4 Automated Statistical Analysis Tool (in progress)

4.0 Security and Data handling

We have been very careful to include the latest advances in Internet security to assure highly secure transmission of data. All data is encrypted while in transit, making it *very* difficult for anyone to obtain the information in a useful format. Further, the data is *authenticated* which means that only those RSVP reporting stations that are registered with the system can actually enter data for use by clinicians and epidemiologists (the data entered into the SNL demonstration site is not “real” data). You will not be able to enter data into the RSVP system from home, from your personal computer, or from some other computer that is not designated as an official RSVP reporting station.

These precautions are taken to ensure the meaningfulness and integrity of the data, and also to protect potentially confidential information. Additional information is available in the **Technical Information section (6.0)** of this User’s Manual.

5.0 Frequently-Asked Questions

1. Why doesn’t RSVP offer differential diagnosis or suggested laboratory tests? Do you plan to do this in the future?

DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

Answer: Past clinical studies and surveys have repeatedly indicated that clinicians do not like “expert systems” for medical diagnosis (the epidemiology community may be different here). Further, there may be liability concerns if RSVP suggested specific diagnoses or tests and the clinician failed to acknowledge them. But, most important, we want RSVP to be a fast, user-friendly clinical and epidemiology tool. We believe that this can be done best by providing needed data that is not usually available to either of these communities.

2. Does RSVP require any special software? Can any computer be used with RSVP?

Answer: RSVP requires only a reasonably up-to-date web browser like Internet Explorer 5.0 or Netscape 4.7 (or later). Both are free and operate on all of the common commercially available computers, including Apple Macintosh and all PCs. However, we have found that a touch screen facilitates rapid data entry, and we recommend one for busy clinics where saving even a few seconds of time can mean the difference between a case being reported or not.

3. What happens to all of the data that I enter? Can I retrieve it later? How do I know who will have access to it and for what purpose?

Answer: All of the data is encrypted and authenticated (see section 3.0 above). It is stored in one of two ways: at a server located in the local public health department; or at a central server at Sandia (which operates as a “virtual server” for multiple public health jurisdiction. The latter configuration is much more cost-effective because only one server needs to be maintained, and any software improvements need be done on only one server. This facilitates rapid correction of bugs, as well as easy archiving of data to assure that information is not lost should a network problem or power failure cause servers to go down. For details on how to download the data, see section 3.0 **The Query Page** for more information.

Local public health authorities control all data from any clinical site. They can decide if the data (including geographic mapping and temporal graphs) are shared with other clinicians and public health officials at other RSVP participating sites. They can also decide if they wish to share some or all of the data with other public health offices in State capitols or with Federal agencies such as the CDC. Thus, data is under control of the lowest-level (i.e. most “local”) public health office. Clinicians and their local public health officials can decide if there are benefits to them to release this information to other epidemiologists or health officials.

DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

Sandia has no intention of releasing data to any other users.

4. Will Sandia use the data for any research purposes?

Answer: Yes. The Sandia principle investigator and his RSVP team are interested in using RSVP data to develop advanced mathematical models of specific diseases, testing the hypothesis that diagnosis of a specific disease entity (e.g. influenza) can be made on the spatial and time distribution of symptoms in a population. We envision that such models could be of great utility to public health offices and clinicians in recognizing communicable disease entry into a community, or even the presence of novel disease entities.

Further, Sandia will, in collaboration with public health officials, study the usefulness of syndrome-based reporting to clinicians and epidemiologists. From time to time, you can expect that there will be survey forms that will appear on the RSVP screen after you have submitted a case. These will be simple questions soliciting your opinion on how RSVP has helped (or not) in case management, and also inviting you to comment on improvements for future versions of RSVP.

5. Is it necessary for most or all doctors to be using RSVP in order for the data to have clinical significance?

Answer: No. Only a statistically significant sampling (generally between 5 and 10%) of clinicians in a given area need be active reporting participants in RSVP so that the data is clinically meaningful. Of course, the more physicians who have access to the data that is collected, the better their clinical practice is likely to be.

6. Will Federal authorities have access to the RSVP system?

Answer: Actually, anyone can look at some of the RSVP, but only a very limited subset; afterall, RSVP is designed to be a knowledge-sharing tool, while at the same time maintaining strict patient and physician confidentiality. Federal authorities (such as the Centers for Disease Control) can view the Feedback summary pages but will NOT have access to the raw data. The raw data remains under the control of local public health authorities in your jurisdiction. They may decide to release the data to other analysts if they wish, but under no circumstances will Sandia's project managers provide information to any officials outside of a local public health jurisdiction without the *explicit* consent of the local officials.

When we say "local public health official" (or authority), we are referring to the State, City or County public health official nearest to the physician doing

the case reporting. In New Mexico, where RSVP began, there really is no “local” public health epidemiologist other than those who work in the state’s capitol, Santa Fe, at the NM Department of Health. Now there are some field offices, but almost all reporting goes directly to the medical and veterinary epidemiologists in Santa Fe. Obviously, in a crowded place, like New York state, the local epidemiologist is usually a person working in the doctor’s city (e.g. New York City) and is employed by the City (in this case, the New York City Department of Health).

By keeping the raw data under the control of the “local” epidemiologist, we minimize the chances that the an official outside of the doctor’s immediate area will have any of the physician names, and hence only the “most local” epidemiologist would ever call the doctor. Most physicians prefer it this way.

7. Is RSVP being used internationally?

Answer: Yes! The country of Singapore is now implementing RSVP (at a very intensive level so there will be statistically significant coverage of the whole population), and we will soon be installing RSVP in Mexico in clinics near the US Border.

8. Will RSVP be commercialized? Will I have to pay for it?

Answer: At some point in time, if RSVP continues to be well accepted in the medical and public-health communities, Sandia National Laboratories will transition the software to a commercial company that can provide support to users, fund upgrades and updates to meet user requirements and requests, and manage what could be a large network on a 24 hour, round-the-clock basis. At the moment, RSVP is free. Sandia can’t speculate about precise commercial costs for the software, but on a per physician basis we believe it will be quite small – perhaps something on the order of \$200 per year (less than \$20 per month)

6.0 Technical Information

RSVP 2.0 Architecture Document

RSVP 2.0 has been designed as a simple to use and quick to deploy syndrome-monitoring system. It is not intended to be a substitute for the required reporting of notifiable diseases or a patient record system, but rather to provide doctors, the state health department, and any national health department a responsive, near real-time snapshot at what is happening with the health of people in any specific area where the system is in use. A small set of data about a patient is collected to provide the local or state health department a faster method to look for trends and allow for faster alerting. RSVP 2.0 is a stand-alone

DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

system, but its data can be shared to a wide variety of other medical systems. In progress is the connection to OpenEMed via the COAS API.

The Interfaces for inputting data and retrieving data are all web based and use 128B SSL for access. The server design is very flexible to allow for a wide number of deploy strategies. A single server can provide access to a huge number of facilities, depending on hardware. Several 100 facilities to a single server are possible, each with a custom interface for inputting and reviewing data. All users within a facility will have the same interface. This single server would typically serve all the facilities under a local/state DOH.

If needed, a single server can also house multiple DOH's facilities separately. We refer to these as "virtual" servers.

Ideally, a National database containing only a tiny subset of the data would exist to allow for National health monitoring at a glance. This server would also provide a larger GIS system to allow for more advanced correlation of the data. Some ideas for data correlation include weather patterns, migration patterns, and agriculture areas (farm/ranch lands). The data subset on this server and the allowed review of this data are flexible so can change based on National needs or medical policies.

All the data is stored in a relational database, which allows for a wide variety of queries, data-mining and other analysis directly. The data can also be outputted in a wide variety of manners to provide the most useful format to each DOH. These methods include human readable email, faxes, or email-pages. Data can be outputted in XML, HTML, CSV, or tab-delimited files. If needed, ODBC or JDBC connections can be allowed with specific permissions from specific sources into the database.

The Data Model for the data is currently very similar to that of the LOINC (<http://www.regenstrief.org/loinc/>) system. RSVP 2.0's data is stored in the format -

DataType:Scale:value (e.g. Temperature:Celsius:36.0|37.0). The table headers in RSVP 2.0 are currently close but not identical to the LOINC data header format. More work will need to be done to finalize the RSVP 2.0 data model and determine what other modifications need to be made.

For security, RSVP 2.0 has been designed to run on a bastion server preferably running Solaris or another well hardened and easy to maintain OS. The selected web server, Apache-SSL, has been tested world wide from a security and reliability standpoint. All other services available on the server are either only accessible internally or via an encrypted tunnel. This architecture is currently under security review by the SNL Red Team (a Nationally recognized Cyber-Security experts group).

DRAFT Version 2.3 (7/21/02)
NOT FOR GENERAL DISTRIBUTION - Do NOT COPY

For further information, or if you have questions, feel free to contact any of the Sandia RSVP program specialists listed at the top of this document.